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Review

# Family-Centered Care for LGBTQ+ Parents of Infants in the Neonatal Intensive Care Unit: An Integrative Review

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Abstract: Background: Having an infant in the Neonatal Intensive Care Unit (NICU) can disrupt parent well-being, the transition to parenthood, and the typical trajectories of infant and child health. For lesbian, gay, bisexual, transgender, queer, or other sexual and gender minority identity (LGBTQ+) parents, this stress may be compounded by health disparities and fear of stigma and discrimination; however, research is lacking about LGBTQ+ parents of infants in the NICU. Objectives: The purpose of this integrative review was to better understand the experiences of LGBTQ+ parents of NICU infants, with a focus on experiences of stigma and discrimination, sources of strength and resilience, and provision of family-centered care. Method: We searched EBSCOHost, ProQuest, Web of Science, and Google Scholar between 30 May 2023 and 18 September 2023 for empirical studies published in English in peer-reviewed scholarly journals in which LGBTQ+ parents shared their experiences with having infants admitted to the NICU. Results: We identified six articles that met inclusion criteria, all of which were qualitative studies that included 12-14 LGBTQ+ parents of NICU infants. Conclusions: LGBTQ+ parents in all studies reported instances of perceived stigma and discrimination while their infants were in the NICU, whereas parents in two studies mentioned strength and resilience, and parents in three studies described elements of family-centered care. There is a need for rigorous research on family-centered NICU care that includes questions about sources of strength and resilience in addition to challenges. We propose that future researchers use community engaged methods to center perspectives of LGBTQ+ parents.

Keywords: NICU; preterm infants; neonatal; LGBTQ+ families; family-centered care; health disparities



Citation: Yinger, O.S.; Jones, A.; Fallin-Bennett, K.; Gibbs, C.; Farr, R.H. Family-Centered Care for LGBTQ+ Parents of Infants in the Neonatal Intensive Care Unit: An Integrative Review. *Children* **2024**, 11, 615. https://doi.org/10.3390/ children11060615

Academic Editor: Licia Lugli

Received: 20 April 2024 Revised: 8 May 2024 Accepted: 16 May 2024 Published: 21 May 2024



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# 1. Introduction

In the U.S., it is estimated that 5.5% of adults identify as lesbian, gay, bisexual, transgender, queer, or other sexual and gender minority identities (LGBTQ+) [1]. Of the 13.9 million LGBTQ+ adults [1] in the U.S., an estimated 29% are rearing children younger than 18 years of age [2]. There are many ways to become a parent (e.g., adoption, surrogacy, donor insemination, etc.), and doing so via assisted reproductive technology (ART) is increasingly common among LGBTQ+ parents [3]. Advances in reproductive technologies, adoption, and more positive attitudes toward diverse families have, in part, contributed to this increase in the use of ART [4]. In conjunction with this growth, research regarding LGBTQ+ parents and families has grown significantly. This research shows positive family outcomes, including satisfying relationships between LGBTQ+ parents and their children, engagement in positive parenting practices, and positive adjustment and development for children in LGBTQ+ families [4–9].

There is evidence that LGBTQ+ parents may be more likely to have infants admitted to the neonatal intensive care unit (NICU) than their cisgender and heterosexual (cis-het)

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counterparts, given their diverse pathways to parenthood. For instance, regarding foster care and adoption, same-sex partners are seven times more likely to adopt or foster children compared to different-sex partners [4]. Infants born into state custody who require foster care are more likely than other infants to be admitted to the NICU because of prenatal drug exposure or lack of prenatal care [10]. Likewise, infants are twice as likely as older children to enter foster care, most frequently due to neglect or parental substance misuse [11], which means that foster parents of infants often meet them in the NICU (or related hospital care settings). Regarding ART, LGBTQ+ parents are proportionately more likely to use forms of ART compared to their cis-het peers [12]. Infants born via ART may be more likely to require a stay in the NICU [13,14]. Lesbian women are more likely to give birth to infants with low birth weight as compared to heterosexual women [15], which is also a risk factor for time in the NICU. For all these reasons, LGBTQ+ parents—compared to cis-het parents—may be more likely to experience having an infant spend time in the NICU.

## 1.1. Family-Centered NICU Care for LGBTQ+ Families

Having an infant admitted to the NICU alters the typical transition to parenthood and can be a traumatic experience [16]. Parents of infants admitted to NICUs report high levels of stress, anxiety, uncertainty, and decreased parenting confidence [17–19] and may face increased risk of mental health challenges such as depression and post-traumatic stress syndrome [20,21]. These adversities have the potential to affect parent-infant bonding, infant development, and parental well-being [22], warranting a deeper evaluation of the current research related to family-centered care for LGBTQ+ parents in the NICU [23]. Family-centered care (FCC) is a philosophy of care aimed at fostering a relationship between healthcare staff and families to plan, deliver, and evaluate the healthcare provided to patients. FCC relies on four basic concepts: dignity and respect, information sharing, family participation in care, and family collaboration. When FCC is successfully implemented, families, patients, and healthcare providers benefit [24]. Researchers have begun to note the usage of FCC in health settings, and more recently, conceptualizations of FCC in the NICU have been expanded to incorporate the principles of (a) respect, (b) diversity, (c) a strengths-based approach, (d) choice, (e) flexibility, (f) information sharing, (g) support, (h) collaboration, and (i) empowerment [25,26].

Despite the growth in research regarding LGBTQ+ parenting, there is still limited knowledge regarding the needs of LGBTQ+ parents when their infants are placed in the NICU, which can lead to non-inclusive hospital policies that are at odds with LGBTQ+ parents' rights to family-centered care, particularly as it pertains to dignity and respect [27]. For example, when required staff trainings for perinatal healthcare professionals focus on cis—and heteronormative—experiences of childbirth, infant feeding practices, and infant care, this can unintentionally exclude the experiences of LGBTQ+ parents, potentially making the transition to parenthood more stressful [27].

In the past five years, several scholars have published clinical protocols [28], case presentations [29], and insights and suggestions based on clinical wisdom and reviews of the best available literature [30–34] on supporting LGBTQ+ families in the NICU, during lactation, and at discharge. To provide family-centered care for LGBTQ+ parents of infants in the NICU, however, it is important to center the perspectives of LGBTQ+ parents themselves and to better understand their experiences in the NICU, particularly since family-centered care emphasizes parent empowerment and the formation of an effective therapeutic relationship with the health team [23]. Researchers have identified gaps in family-centered care for families of color and from low socioeconomic status who have had infants in the NICU [35], but the perspectives of LGBTQ+ parents of infants in the NICU regarding family-centered care have not been studied. To our knowledge, the experience of having a child in the NICU has not been explored among LGBTQ+ parent families through an integrative review. In this paper, we address this gap in the literature by presenting an integrative review of research on the experiences of LGBTQ+ families in the NICU, which we hope will provide information on the provision of family-centered care for LGBTQ+

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parents. In articulating our rationale for this review, we first describe research on health disparities and experiences of stigma and discrimination among LGBTQ+ families, as well as potential sources of support and resilience for LGBTQ+ families.

### 1.2. Health Disparities, Stigma, and Discrimination among LGBTQ+ Families

Health disparities are "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations" [36], including LGBTQ+ people. LGBTQ+ people often present with poorer mental and physical health outcomes compared to their cisgender and heterosexual counterparts [37]. These health disparities are a result of social and systemic barriers that negatively impact LGBTQ+ individuals and lead to inequitable treatment based on sexual orientation, gender identity, or gender expression (SOGIE). Health equity is the aspirational idea that all people should have the highest possible standard of health, with special attention paid to the needs of people who are at the greatest risk of poor health based on social conditions [38]. To achieve health equity, obstacles to health must be removed [39], and health disparities must be eliminated.

LGBTQ+ individuals in general [40], and specifically LGBTQ+ parents [41], experience stigma, discrimination, and denial of their civil and human rights based on SOGIE, which may culminate in disparate health outcomes. Stigma happens when the labeling of human differences and negative stereotyping of those differences lead to separation, status loss, and discrimination of labeled people [42]. Individuals who identify as LGBTQ+ are often stigmatized due to their group membership and their non-conformity with cis-het norms [43]. Luoma et al. [44] described and defined three forms of stigma (enacted, self, and perceived). Self-stigma refers to negative thoughts and feelings about oneself that come from identification with a stigmatized group. Perceived stigma refers to beliefs that members of a stigmatized group have about stigmatizing attitudes and actions from others in society. Enacted stigma is directly experienced social discrimination, such as interpersonal rejection or difficulty accessing healthcare, employment, or housing. Discrimination can be thought of as the unjust or prejudicial treatment of people on the grounds of their demographic identity, including sexual orientation and gender identity.

Unfortunately, stigmatizing and discriminatory experiences persist across a wide range of settings for LGBTQ+ individuals. A 2020 study found that 15% of the 1528 LGBTQ+ participants indicated they had postponed or avoided medical treatment due to fear of discrimination [45]. Accounts of NICU clinicians revealed that this fear of discrimination is not unfounded and may occur in the NICU. In a study by Sigurdson and colleagues, some NICU nurses reported discomfort with non-heteronormative families that lead to disparities in care, with 4% of clinician accounts addressing disparities in care related to sexual orientation or family status and 4% addressing disparities in care related to gender. Many nurses who participated in this study suggested that "biased attitudes and offensive language likely result in vulnerable families spending less time in the unit with their babies or engaging less with NICU clinicians because of a lack of trust and rapor [sic] with clinicians" (p. 4, [46]). The types of neglectful care, judgmental care, and systemic barriers to care that Sigurdson and colleagues revealed exist in the NICU highlight a lack of equitable family-centered care for LGBTQ+ parents. These disparities in care likely lead to avoidance or postponement of perinatal care, which could lead to negative health outcomes for infants and parents in LGBTQ+ parent families [46-48].

Neonatal clinicians and family advocates have identified SOGIE and family status as factors related to disparities in NICU quality of care [46]; coupled with the added discrimination facing LGBTQ+ parents, we assert that LGBTQ+ families are at a higher risk for deleterious health outcomes associated with their infant's admittance into an NICU. LGBTQ+ parents may also draw from unique sources of support and resilience in coping with stressors [49,50], such as those related to having an infant child in the NICU and/or experiencing discrimination.

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# 1.3. Sources of Support and Resilience for LGBTQ+ Families

Despite pervasive stigma, discrimination, and health disparities, LGBTQ+ people also demonstrate resilience in the context of adversity and often draw from unique sources of support. They do this through integrated positive LGBTQ+ identities [51], "chosen" family [50,52], a sense of LGBTQ+ community belonging [53], and affirming LGBTQ+ climates [54]. The theoretical and conceptual framework of queer family resilience [50,55] is apt for explaining positive adjustment and well-being that LGBTQ+ people, including parents and their children, often experience despite institutional and interpersonal stigma, discrimination, and bias. Considering such a strengths-based approach, and moving away from a damage-centered one [56], allows for acknowledgement of individual characteristics (e.g., flexibility, adaptability), behaviors (e.g., coping strategies), and relational processes (e.g., family communication, LGBTQ+ parent family socialization) that contribute to healthy functioning [50] amidst minority stress. Minority stress theory [57,58] posits that people with minoritized identities (e.g., sexual, gender) experience stress resulting from stigma and discrimination at interpersonal and institutional levels. Applying a minority stress framework without attending to positive qualities, experiences, and strengths, however, can inadvertently pigeonhole LGBTQ+ people and their families as without power, agency, resources, or hope [59]. Thus, it is important to understand the experiences of LGBTQ+ NICU parents specifically, including potential harm from discrimination but also wells of support and resilience. Generating this understanding represents one step toward decreasing barriers to family-centered, inclusive NICU care and health equity for this population. The purpose of this integrative review is to better understand the experiences of LGBTQ+ parents of NICU infants. Specifically, we addressed the following research question and sub-questions:

Based on published, peer-reviewed, empirical research, what is known about the experiences of LGBTQ+ parents when their infants are in the NICU? Specifically, to what extent and in what ways...

- ...do LGBTQ+ parents experience stigma and discrimination when their infants are in the NICU?
- ...do LGBTQ+ parents draw on sources of strength and resilience when their infants are in the NICU?
- ...is family-centered care discussed in the relevant literature on LGBTQ+ parents of infants in the NICU?

## 2. Materials and Methods

We engaged in the following stages of integrative review outlined by Whittemore and Knafl [60]: (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis, and (5) presentation. To promote transparency and increase methodological rigor, we also attempted to adhere to PRISMA guidelines for systematic reviews [61] when appropriate. As this review was exploratory, we did not register or publish our review protocol prior to this publication.

## 2.1. Inclusion and Exclusion Criteria

We determined the following inclusion criteria for our integrative review:

- Peer-reviewed articles in scholarly journals;
- Published in English;
- Primary empirical research (qualitative, quantitative, mixed-methods, or descriptive);
- Focused on the experiences of LGBTQ+ parents of NICU infants.

We acknowledge that only including peer-reviewed articles published in scholarly journals increases the risk of publication bias; nevertheless, we felt it was appropriate to exclude theses and dissertations to (a) add a component of quality control through the peer-review process and (b) focus on research that healthcare professionals would be most likely to access via scholarly journals. In the interest of time and because we chose to conduct an integrative review rather than a scoping review, we did not search conference proceedings

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or white papers. We had no exclusion criteria related to the years of publication or the country in which the study was conducted. Given the resources available to the research team, we chose to focus on articles published in English. Exclusion criteria consisted of the following:

- Articles not published in English;
- Secondary research (reviews);
- Expert opinion;
- Case studies;
- Theses or dissertations;
- Gray literature (conference proceedings, white papers);
- Research that included LGBTQ+ parents as participants but did not provide information about their experiences in the NICU;
- Research on NICU parents' experiences that did not specify whether participants identified as LGBTQ+.

## 2.2. Search Strategy

We searched EBSCOhost, ProQuest, and Web of Science databases between 30 May 2023 and 5 June 2023 for articles with the following terms in the article text: (LGBT\* OR lesbian OR gay OR bisexual OR transgender\* OR transsexual OR queer OR intersex OR asexual OR pansexual OR non-binary OR "sexual and gender minority" OR SOGIE) AND (parent OR family) AND (NICU OR "neonatal intensive care unit"). We used database search filters to limit our search to peer-reviewed articles published in English. Follow-up searches between 30 August 2023 and 18 September 2023 of Google Scholar using the terms (LGBT OR lesbian OR gay OR bisexual OR transgender OR queer OR intersex OR asexual OR pansexual OR non-binary OR "sexual minority" OR "sexual and gender minority" OR SOGIE) AND NICU revealed over 1000 hits for many search terms; since there were no eligible studies apparent in the Google Scholar results after the first few pages of results, we only looked at the first eight pages of each of the Google Scholar searches.

See Figure 1 for a flowchart of study identification, screening, and inclusion of articles [61]. One author (first) identified, screened, and retrieved records after consulting with a research librarian regarding the search strategy. Next, to reduce risk of bias, two of the authors (first, last) independently assessed each of the 28 records retrieved for eligibility. To manage bias in the rating process, we first created a scoring sheet with eligibility criteria for each individual record, including whether each record represented (yes/no) (a) primary research (not a review, meta-analysis, or case presentation), (b) peer-reviewed research published in a scholarly journal (not an editorial, white paper, conference proceeding, dissertation or thesis, or other non-peer-reviewed work in a newsletter or other source), and (c) included samples of LGBTQ+ identified parents of NICU infants (not other samples of parents or not focused on experiences in the NICU specifically). Individual records (n = 28) were then independently reviewed and rated by each of the two authors, who examined the source of each record, the type of research or content represented, and the samples included. If records were rated as yes for all three overarching criteria, they were deemed eligible for inclusion in our integrative review (if any criterion was scored as no, the record was ineligible). The two raters had 100% agreement in their ratings of inclusion criteria across the 28 records.

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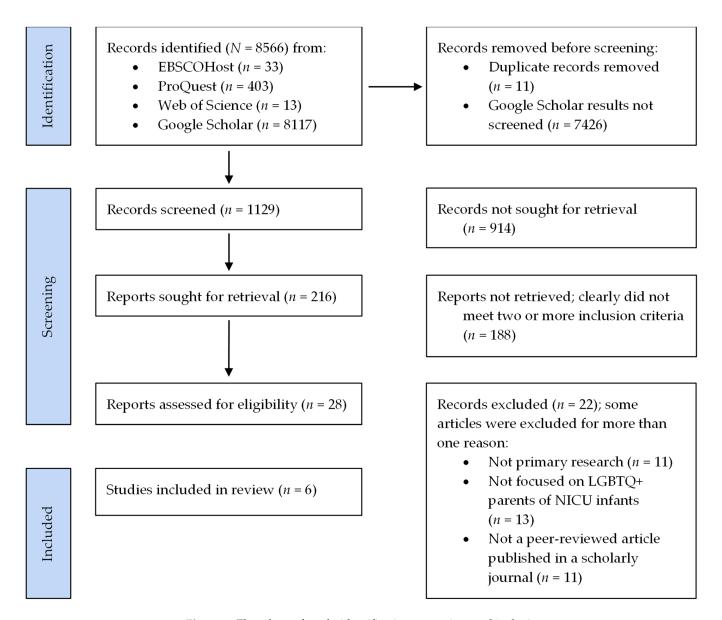


Figure 1. Flowchart of study identification, screening, and inclusion.

# 3. Results

We identified six qualitative research studies, published in English in peer-reviewed scholarly journals, in which LGBTQ+ families of infants in the NICU were interviewed about their experiences. Characteristics of included studies are shown in Figure 2. Studies that initially appeared to meet inclusion criteria during the screening phase but were excluded after assessment for eligibility are shown in Supplementary Materials (Figure S1).

Although there was a total of 150 participants across these six studies, only 12 to 14 participants, all of whom identified as cisgender women, discussed having infants in the NICU. We report the range 12 to 14 participants because it appears that one group of authors shared the experiences of the same participant, Kendra, in two studies [62,63], and in one study [64], the authors reported the number of infants admitted to the NICU (two) rather than the number of parents of these infants interviewed (three or four, depending on whether they interviewed two couples or a couple and a parent, which is unclear). Although some included studies presented findings on broader experiences of LGBTQ+ parents outside of acute healthcare settings, here we solely report those findings related to LGBTQ+ parents' experiences in the NICU, beginning with the earliest study.

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First Author, Year	Purpose	Participants	Design Type and Method
Hudak, 2023	To explore how queer pregnant couples encountered heterosexism within patient-provider interactions.	Queer pregnant couples ( $N = 16$ , or 32 participants). One couple and one co-mother ( $n = 3$ ) spoke of their experiences in the NICU.	Qualitative. Conducted 46 interviews and used multiadic analysis, grounded in a critical foundation.
Kellas, 2012	To discuss lesbian mothers' responses to discursive legitimacy challenges.	Lesbian mothers ( $N$ = 44). One spoke of her experience in the NICU ( $n$ = 1).	Qualitative. Conducted ten focus groups and coded responses using the theoretical framework of remedial accounts.
McKelvey, 2014	To develop a metastory of nonbiological lesbian mothers' postpartum experiences	Nonbirth lesbian mothers ( $N = 10$ ). Four spoke of experiences in the NICU ( $n = 4$ ).	Qualitative. Conducted interviews and applied thematic narrative analysis utilizing Riessman's structural approach to thematic analysis.
Renaud, 2007	To describe lesbians' personal and health care experiences of becoming pregnant, giving birth, and being mothers and comothers within the context of potentially oppressive family, social, and political structures.	Lesbian women ( $N = 70$ ). Two infants required intensive care ( $n = 3-4$ lesbian women).	Qualitative. Engaged in in-depth open-ended interviews, focus groups, and participation observation. Conducted content/categorical analysis followed by discussion and critical conversation.
Ril, 2023	To understand the challenges faced by double-motherhood in Brazil.	Brazilian cisgender, non- heterosexual women who are mothers ( $N = 9$ ). One spoke of her experience in the NICU ( $n = 1$ ).	Qualitative. Led nine interviews and one focus group and conducted thematic analysis.
Suter, 2015	To consider the meaning(s) of motherhood in female–female co-motherhood.	Female co-parents ( $N$ = 42). One spoke of her experience in the NICU ( $n$ = 1).	Qualitative. Engaged in ten focus groups and carried out contrapuntal analysis.

**Figure 2.** Details of included studies [62–67].

# 3.1. Findings from Included Studies

Renaud [64] wrote about childbearing experiences of lesbian families. Using a critical ethnography design, she interviewed 21 English-speaking self-identified lesbian women from cities and rural communities in the Pacific Northwest, conducted focus groups with three lesbian couples, and observed an estimated 43 participants in a support group. Two babies of participants interviewed by Renaud required stays in the NICU. One couple had a positive NICU experience, whereas the other couple's experience was less positive. Components of the positive NICU experience included the co-mother being able to see the baby immediately after delivery and having healthcare professionals encourage her to speak to the baby, acknowledging that the baby would recognize the co-mother's voice because she had been present during the entire pregnancy. Having NICU staff treat both the birth mother and the co-mother equally well, involving them in the care of their infant immediately after birth, was another important part of this lesbian couple's positive NICU experience. The other family whose child was admitted to the NICU reported that next-of-kin rules prevented the co-mother from visiting their infant in the NICU.

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Kellas and Suter [62] studied lesbian, bisexual, and sexually fluid mothers over the course of 10 focus groups with 44 female co-parents at urban universities in two primarily rural states, using the theoretical framework of remedial accounts to discuss external family challenges. One of the challenges that emerged was related to healthcare master narratives. One non-biological mother, Kendra, whose son spent several weeks in the NICU reported that she did not get to hold her son the first day he was born, even though her partner, the birthing parent, did. When she asked why she could not hold her son, Kendra was told she "wasn't family". She reported that this "was probably the most negative experience" she had ever had. The healthcare provider's challenge to Kendra's legitimacy as a parent made this already stressful time (during which she was worried about whether her son would have brain damage and ever be able to walk or talk) even more stressful and negative. Kendra had to prove her legitimacy as a parent by demonstrating that she had Power of Attorney for her partner, at which point the doctor gave her information about her son in the NICU.

Suter and colleagues [63] later published a study on competing discourses of comothers based on the focus groups they described in Kellas and Suter [62]. They shared Kendra's account of not being allowed to hold her son in the NICU as an example of how the discourse of essential motherhood defines authentic motherhood based on biology, wherein the biological mother is the only real mother.

McKelvey [65] interviewed ten nonbirth lesbian mothers from nine different states to develop a meta story of their postpartum experiences within the first year after their child's birth. Four participants had infants who were admitted to the NICU, and all spoke of the experience as a positive one. Characteristics of NICU care that made the experience positive for nonbirth mothers were being (a) included in their babies' care, (b) recognized as equal mothers, and (c) treated with respect. One participant spoke of the NICU experience being one that "affirmed [her] as a mother", since the nonbirth mother was asked to accompany their baby to the NICU, make decisions, provide information, and report back to her family because the birth mother had not yet delivered the placenta. Another described a crib card that NICU nurses made that listed both mothers' names; as a new mother, this gesture felt very special. Although parents described experiences in the NICU as positive, one participant spoke of the financial hardship that their baby's stay in the NICU caused, exhausting the family's financial savings, which made the cost of the second-parent adoption process more of a financial strain.

Hudak [66] wrote about heterosexism in healthcare settings, interviewing 16 queer pregnant couples from 12 different states together and separately and engaging in critical analysis to identify themes surrounding patient–provider communication and heterosexism. One couple (Sydney and Amber) reported that when their child was admitted to the NICU, Amber, the co-mother, had a stressful encounter with a security guard outside the NICU who doubted Amber's assertion that she was the child's mother because she had not just given birth. This interaction demonstrates how heterosexist assumptions about motherhood can make the NICU experience even more stressful for queer parents. Another co-mother, Ava, talked about how grateful she was to the nurse who showed her how to provide basic care for her son in the NICU (testing his blood sugar and temperature, changing his diaper, and feeding him), stating that this helped her feel included and like the nurse considered her a mom.

Ril et al. [67] sought to better understand the experience of double motherhood, which is the "shared experience of motherhood between two non-heterosexual cisgender women" (p. 2) by interviewing and conducting online focus groups with nine Brazilian cisgender lesbian or bisexual women who were mothers. One participant, Cloe, shared that she was not allowed to go with her daughter to the NICU because Cloe was a non-biological mother.

In the next two figures, we summarize the connection between the findings of the included studies described above and our sub-questions regarding LGBTQ+ parents' (a) experiences of stigma and discrimination, (b) sources of strength and resilience, and (c) perceptions of family-centered care when their infants were in the NICU (see Figure 3),

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in addition to including quotes from parents in included studies related to positive and negative experiences with NICU staff (Figure 4).

First Author, Year	Instances Noted (X)			Explanation (Bold text indicates keywords related to instances of stigma/discrimination,	
	1	2	3	strength/resilience, or family-centered care.)	
Hudak, 2023	Х		Х	A security guard demonstrated <b>discrimination</b> by initially forbidding a co-mother (Amber) to enter the NICU because he was confused about how she could be the child's mother if she had not given birth. One co-mother (Ava) mentioned appreciating when providers actively involved her in basic care in the NICU (feeding, testing blood sugar, checking temperature, changing diaper), indicating <b>support</b> , <b>collaboration</b> , and <b>empowerment</b> .	
Kellas, 2012	Х	Х		Kendra, a NICU co-parent, experienced <b>discrimination</b> in the form of a challenge to her parental legitimacy when a nurse refused to let her hold her infant because she "wasn't family." Kendra showed she had Power of Attorney for her partner so that the doctor would give her information about her partner and infant in the NICU. Proving her legitimacy as a parent in this way could be seen as a source of <b>strength</b> .	
McKelvey, 2014	X	X	X	One mother spoke of financial hardship (on top of an expensive NICU stay) caused by having to adopt her baby because she was not legally recognized as the baby's mother. This represents a form of legal discrimination. One nonbirth mother shared that her daughter being in the NICU affirmed her as a mother because staff relied on her to make decisions and provide information while the birth mother was recovering. Even though she had no legal rights to her baby, she felt that the NICU staff respected her as a mother. Nonbirth lesbian mothers perceived their baby being in the NICU as beneficial to them as mothers. All participants who had infants in the NICU reported positive interactions with NICU providers in which they felt included in their babies' care and recognized as equal mothers who were treated with respect, indicating respect, information sharing, collaboration, empowerment. One shared how a NICU nurse made a crib card that listed the names of both mothers, demonstrating an understanding of diversity and flexibility.	
Renaud, 2007	Х		Х	Next-of-kin rules prevented same-sex parents from visiting in hospital intensive-care units, representing <b>discrimination</b> . One couple reported having a positive experience in the NICU, where both mothers received hospital bracelets so they could visit the NICU, were treated equally well by NICU staff, and were able to be involved in their baby's care, demonstrating <b>respect</b> , <b>support</b> , <b>collaboration</b> , <b>information sharing</b> , and <b>empowerment</b> .	
Ril, 2023	х			A co-parent (Cloe) was not permitted to accompany her daughter in the NICU, representing discrimination.	
Suter, 2015	Х			Kendra's account of not being allowed to hold her son in the NICU (see Kellas, 2012) was described as an example of discourse of essential motherhood, which resulted in <b>discrimination.</b>	

1 Instances of stigma or discrimination, 2 Instances of strength of resilience, 3 Instances of family-centered care

**Figure 3.** Instances of stigma/discrimination (1), strength/resilience (2), and family-centered care (3) for LGBTQ+ parents of NICU infants in included studies [62–67].

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# Positive Experiences (including Family Centered Care) with NICU Staff

# Negative Experiences (including Stigma/Discrimination) with NICU Staff

Ava, a co-mother, talked about how the NICU providers treated her as the mother by allowing her to do some of the basic care. She talked about her experience in her individual interview:

When he [son] was in the NICU, they were doing feeding every three hours and so there was a whole routine to it where we would test his blood sugar and then his temperature, change his diaper, and then we would feed him. And I got to do that almost every time because the nurse walked me through it a couple of times and then let me kind of run the show.

Ava was grateful to the nurses who allowed her to perform this care for her child. She actively felt that she was included and considered a mom, particularly during the difficult time of her child being in the NICU (Hudak, 2023, p. 121).

The birth mother could not visit right after the delivery, but the comother was able to see the baby. Her first interaction with their daughter happened right after birth in the NICU:

They said, 'talk to her ... She knows who you are!' Assuming I'd been there for the whole pregnancy. Of course ... and when I did, she immediately turned her head around and looked at me when I started talking to her (Renaud, 2007, p. 197).

When Sydney gave birth, their child had to be taken to the NICU. Amber followed their child to the NICU while Sydney was in recovery. As Amber accessed different areas of the hospital, she introduced herself as the mother, creating confusion for the staff, as she had not just given birth. The confusion led to an encounter with the security guard outside the NICU. Amber shared her story in the couple interview:

He was like, 'How can you be the mother? Like you just gave birth?' And I was like 'No, it's my wife' ... the midwife had to like break it down for him because it was just like, are you freaking kidding me? Like my kid is in the NICU, like I need to go (Hudak, 2023, p. 118).

...Kendra narrated a health care challenge when her partner gave birth to their son who after complications spent several weeks in the Neonatal Intensive Care Unit (NICU):

My partner got to hold him that first day, uh, but I still didn't get to hold him, uh, and I was kind of freaking out, cause they told us that he was...better than a fifty percent chance that he was gonna be brain-damaged, that he was never gonna walk, he's never gonna talk...it had been now three days and...I asked if I could hold him, and the nurse said I couldn't, and I asked why not, and she said *cause I wasn't family*. So that was probably the most negative experience that I've ever had (Kellas, 2012, pp. 78-79) [emphasis added by Kellas].

**Figure 4.** Quotes from LGBTQ+ parents who were participants in included studies about positive or negative experiences with NICU staff [62,64,66].

# 3.2. Rigor of Included Studies

Because all the included studies were qualitative, we did not assess risk of bias; instead, here we report efforts authors took to ensure rigor based on criteria appropriate for qualitative research. Authors of five of the six studies reported steps they took to ensure rigor, although none specifically used the term rigor. McKelvey [65] reported that they followed Riessman's criteria for trustworthiness, which consisted of persuasiveness, coherence, correspondence, pragmatic use, and social justice. Renaud [64] included a table outlining steps they took to ensure validity, specifically (a) prolonged engagement in the field, (b) triangulation of data sources, (c) distinguishing observations from researcher's interpretation, (d) peer debriefing, (e) looking for negative cases, (f) thick description, (g) using non-leading questions, (h) audit trail, (i) ironic validity, (j) rhizomatic validity, (k) paralogic validity, and (l) voluptuous validity. Kellas and Suter [62] reported steps they

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took to establish validity of their coding scheme and to calculate unitizing reliability and intercoder reliability. To ensure the validity of their findings, Suter and colleagues [63] reported that the research team (a) maintained an analytic audit trail of data analysis and analytic decisions, (b) included data exemplars in the results section to demonstrate the link between raw data and analysis, and (c) used investigator triangulation and referential adequacy to verify the initial thematic analysis and interplay analysis. We were not able to find specific mentions of steps taken to enhance rigor in the studies by Hudak [66] and Ril and colleagues [67].

#### 4. Discussion

In this study, we sought to learn about the experiences of LGBTQ+ parents with NICU infants; in particular, we examined the experiences of stigma, discrimination, resilience, and family-centered care reported in six studies that focused on NICU experiences and included LGBTQ parents. Here, we discuss the findings from the included studies in the context of our research questions and discuss connections between our findings and the existing literature.

### 4.1. Stigma and Discrimination Reported by Parents in Included Studies

We found that descriptions of discrimination (also sometimes known as enacted stigma) emerged from participants from all six studies within our review. There is extensive research showing that perceived discrimination is associated with decrements in health [68]. Previous research has identified that LGBTQ+ individuals experience dissatisfaction with healthcare settings, are less likely to seek healthcare services compared to non-LGBTQ counterparts, and experience negative communication with healthcare professionals [45,47,48].

We would be remiss if we did not discuss the effects of the U.S. Supreme Court case Obergefell v. Hodges [69] and the impact this decision has had on legal discrimination in healthcare for LGBTQ+ individuals in the United States. Obergefell v. Hodges dealt with the constitutionality of state bans on same-sex marriage. As a result of the 2015 decision, same-sex marriage was effectively legalized across the United States. This landmark case profoundly impacted the legal landscape regarding LGBTQ+ rights in the U.S. Importantly, some obstacles to health equity were removed or minimized (i.e., access to federal marriage equality for same-gender couples, access to joint parent adoptions as same-gender partners across all 50 states). One implication for LGBTQ+ parents with hospital birthing experiences (among others) is that when same-gender partners who become parents are legally married, the birth certificate of their child can reflect both partners as the parents, guaranteeing non-birthing parents their parental rights. Four studies included in our review were conducted in the U.S. prior to this 2015 case [62–65]. Parents in these studies mentioned experiences that we would (likely) expect no longer occur in the U.S. as a result of Obergefell v. Hodges; namely, co-mothers in these studies were not considered the legal parents of their infants because they could not legally marry the child's birthing mother and were denied certain parental rights in the NICU (e.g., holding their infant, caring for their infant). However, even though the study by Hudak [66] was published more than five years after the Obergefell v. Hodges decision, Amber, a parent interviewed by Hudak, reported experiencing discrimination from an NICU security guard because her child had two mothers.

# 4.2. Sources of Strength and Resilience Reported by Parents in Included Studies

Parents in two of the included studies [62,65] alluded to sources of strength or resilience during their infants' NICU experiences. In the study by Kellas and Suter [62], one co-mother, Kendra, showed she had Power of Attorney for her partner so that the doctor would give her information about her partner and infant in the NICU; proving her legitimacy as a parent in this way could be seen as a source of strength via knowledge and resources. In McKelvey's [65] article, one nonbirth mother shared that her daughter being in the

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NICU affirmed her as a mother because staff relied on her to make decisions and provide information while the birth mother was recovering. Even though she had no legal rights to her baby, the nonbirth mother felt that the NICU staff respected her as a mother. Nonbirth lesbian mothers in McKelvey's study perceived their babies being in the NICU as beneficial to them as mothers because it helped legitimize their roles as parents [65]. These experiences highlight the importance of LGBTQ+ parents having choice, agency, self-efficacy, decision-making power, and the trust of staff in the context of having an infant in the NICU, all of which constitute sources of strength and resilience. In addition, these findings align with the broader literature about the lengths that LGBTQ+ parents frequently employ to ensure legal and practical security for their families [50].

Although we were able to infer sources of strength from the included studies, none of the authors of the included studies specifically named sources of strength or resilience as such. This could be because authors of five of the included studies designed their interview questions to elicit information about challenges experienced by LGBTQ+ parents, namely heterosexism [66]; discursive legitimacy challenges [62,63]; being mothers and co-mothers within the context of potentially oppressive family, social, and political structures [64]; and challenges faced by double-motherhood [67]. By contrast, McKelvey [65] simply asked participants to tell the story of their postpartum experiences, without explicit focus on challenges faced. However, none of the authors of included studies specifically asked participants about sources of strength and resilience when their infants were in the NICU.

# 4.3. Examples of Family-Centered NICU Care in Included Studies

We also sought to understand what the current literature could reveal about the use of family-centered care for LGBTQ+ parents in the NICU. As noted in the background, family-centered care is a philosophy of care aimed at fostering a relationship between healthcare staff and families to plan, deliver, and evaluate the healthcare provided to patients, and it relies on four main principles (dignity and respect, information sharing, family participation, and collaboration). In only one study [65] in our review did the authors explicitly discuss family-centered care. The authors posited the importance of engaging in family-centered care with LGBTQ parents. However, in other studies, LGBTQ+ parents of infants in the NICU mentioned positive interactions with healthcare professionals in which they experienced care in line with the principles of FCC. For example, some participants in the included studies reported having positive experiences in the NICU when hospital staff (a) affirmed their roles as parents by showing them how to care for their children [65,66] and (b) treated both mothers equally well, including both mothers' names on the infant's crib card [65] or acknowledging that the baby would recognize the non-birthing mother's voice as well as the birthing mother's voice [64].

Being able to see the baby immediately after delivery [64] and helping to make decisions about their infants' care [65] also made participants feel respected and affirmed as parents during their infant's NICU stay. As such, in contrast to experiences of discrimination, we suggest that NICU and hospital personnel engaging in family-centered care can contribute to building resilience among LGBTQ+ parents with a baby in the NICU. Practitioners can emphasize unique strengths among LGBTQ+ parents and cultivate their connection to various support resources, which may be LGBTQ+-specific. When LGBTQ+ parents feel supported, and have access to necessary resources, these dynamics promote the positive health and development of their NICU infants. These processes are not necessarily unique to LGBTQ+ parents, yet LGBTQ+ parents may be able to draw from unique sources of support, such as from having a positive, integrated LGBTQ+ identity; connections and sense of belongingness to LGBTQ+ community; and chosen family [50].

# 4.4. Limitations of This Integrative Review

Our integrative review should be considered within the context of its limitations. First, the relevant literature that met inclusion criteria was limited, and all studies were qualitative. The few articles on the topic point to a need to focus future research on the

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LGBTQ+ parent experience in the NICU, including larger and broader samples of LGBTQ+ parents. Second, our search was restricted by the authors' language limitations. The authors are native English speakers and do not fluently speak other languages; thus, our search was limited to articles written in English. We acknowledge that only including articles in English may have limited our results in terms of geographic and cultural contexts. Our findings must also be considered in the context of the participants captured in each individual study. Participants from all six articles identified as cisgender women, thus limiting the understanding of trans or non-binary individuals and gay men who may have adopted a child placed in the NICU. Lastly, we did not include "gray literature" in our search, thus limiting the potential studies conducted through dissertations, thesis work, or from non-academic institutions and organizations. Despite these limitations, our study contributes to the body of research literature, and our limitations point to important considerations for future research.

#### 4.5. Suggestions for Future Research

Given that so few studies (n = 6) have directly addressed the experiences of LGBTQ+ parents who have an infant in the NICU, and so few participants were represented in these six studies (n = 12-14), as revealed by our integrative review, more research is needed on this topic. We recommend further qualitative, descriptive, and mixed-methods research to develop a larger body of evidence related to LGBTQ+ parents of NICU infants. Conducting research with the population through community-based participatory research methods would be ideal, as participants can work with researchers to inform the direction of the research and identify the needs of the community (i.e., research with participants, not on them). Furthermore, in light of past harm caused to the LGBTQ+ community by certain researchers [5], there is an ethical imperative for researchers to engage in communityengaged research practices that ensures respect and recognition of members of the LGBTQ+ community by centering their perspectives and including them throughout the research process. Research related to healthcare professionals who work with this population is greatly needed, as is research on perceived stigma among LGBTQ+ parents of NICU infants. Finally, the literature regarding LGBTQ+ individuals and their families more broadly needs to center on a strengths-based perspective. As it stands, much of the research is deficitfocused, despite the strength and resilience exhibited by the LGBTQ+ population [50].

#### 4.6. Suggestions for Healthcare Professionals and LGBTQ+ Parents

Here, we highlight recommendations that parents in the included studies made for parents and healthcare professionals to center the perspectives of LGBTQ+ parents. Participants in Kellas and Suter's [62] study offered suggestions to other female coparents, including (a) be yourself and be a model for others, (b) manage your emotions, (c) surround your family with positive people, and (d) focus on the kids. Renaud [64] reported that participants had negative experiences with the healthcare system in general, which has implications for NICU providers, including (a) intake forms that were not inclusive of lesbian partners, (b) staff not understanding issues important to lesbian families, and (c) a lack of recognition of the partner if the birth mother or infant experienced an emergency, death, or illness. This information has implications for parents, who may unfortunately still be faced with navigating these challenges, and for healthcare providers, who can be proactive in removing these obstacles for LGBTQ+ parents in the NICU to promote health equity.

Parents interviewed by Hudak [66] offered the following advice for healthcare professionals: (a) include the co-parent, (b) actively involve both parents in infant care, (c) screen co-parents for depression, (d) treat partners as equals, (e) pay attention to language and assumptions, (f) ask rather than assume, and (g) make notes for future visits so that parents do not have to constantly explain. Other suggestions from parents interviewed by Hudak included (a) asking LGBTQ+ parents open-ended questions to better understand what is important to them; (b) using parent's pronouns; (c) acknowledging any mistakes, apologiz-

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ing, and moving on; and (d) advocating for queer parents. The interaction that Amber and Sydney, mothers interviewed by Hudak, had with the security guard highlights the need for training in the provision of LGBTQ+-affirming care to involve all staff in a healthcare system who may engage with parents, not just physicians and nurses.

#### 5. Conclusions

The purpose of this integrative review was to examine the current literature regarding the experiences of LGBTQ+ parents of NICU infants. Of primary importance, we sought to understand experiences of stigma, discrimination, strength, resilience, and family-centered care. Our search yielded six articles that met the inclusion criteria. Participants from all six studies discussed experiences that can be categorized as stigma or discrimination, whereas parents in two studies discussed experiences that were indicative of strength and resilience. Although participants in three studies described experiences consistent with principles of family-centered care, only one author specifically noted family-centered care. Our findings highlight the need for more methodologically diverse, community-engaged research on the perspectives of LGBTQ+ parents in the NICU setting.

**Supplementary Materials:** The following supporting information can be downloaded at https://www.mdpi.com/article/10.3390/children11060615/s1, Figure S1: Studies that initially appeared to meet inclusion criteria during the screening phase but were excluded after assessment for eligibility. References [70–84] are cited in Supplementary Materials.

**Author Contributions:** Conceptualization, methodology, and funding acquisition, O.S.Y., A.J., K.F.-B., C.G. and R.H.F.; formal analysis, O.S.Y. and R.H.F.; data curation, O.S.Y., R.H.F. and C.G.; writing—original draft preparation, O.S.Y., A.J., C.G. and R.H.F.; writing—review and editing, O.S.Y., A.J., K.F.-B., C.G. and R.H.F. All authors have read and agreed to the published version of the manuscript.

**Funding:** This research was funded by the University of Kentucky Center for Health Equity Transformation (CHET) and Center for Clinical and Translational Science (CCTS) pilot grant. This publication was supported by the National Center for Research Resources and the Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR001998. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

**Data Availability Statement:** The raw data supporting the conclusions of this article will be made available by the authors on request.

**Acknowledgments:** Thank you to Sabrina Beiring, Nita Kulkarni, and Casper Moore for assistance with data extraction and table creation; and to Zach Palma for editorial assistance.

Conflicts of Interest: The authors declare no conflict of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

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